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Original article

A European network for the investigation of gender incongruence: The ENIGI initiative

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ABSTRACT

Studies on diagnostic subtypes of gender identity disorder (GID) or gender incongruence (GI), comorbidity and treatment outcome show considerable variability in results. Clinic/country specific factors may account for the contradictory results, but these factors have never been studied. This article is the first of a series reporting on a unique collaborative study of four European gender identity clinics (the European network for the investigation of gender incongruence [ENIGI]). Here, we present the diagnostic procedures of the four clinics (Amsterdam, Ghent, Hamburg, and Oslo), the standard battery of instruments, and the first results regarding applicants with GI who seek treatment. Applicants in the four clinics did not differ in living situation, employment status, sexual orientation, and age of onset of GI feelings. However, the Amsterdam and Ghent clinic were visited by a majority of natal males, whereas Hamburg and Oslo see more natal females. Male applicants were older than female applicants within each country, but female applicants in one country were sometimes older than male applicants in another country. Also, educational level differed between applicants of the four clinics. These data indicate that certain sociodemographic and/or cultural characteristics of applicants have to be taken into account in future studies.

1. Introduction

"Gender incongruence" refers to the incongruence between one's experienced/expressed gender on the one hand, and one's assigned gender and/or one's congenital primary and secondary sex characteristics on the other hand. [25]. Individuals with GI form a heterogeneous group. In the literature they are known under various names: transsexuals, gender queer, gender variant, transgender individuals, individuals with gender dysphoria, or individuals with gender identity disorder. The last term is the name of the current DSM-IV-TR [1] diagnosis and refers, like transsexualism (ICD-10) [31], to extreme gender dysphoria only. In this paper, we will use the term GID only when we refer to the clinical diagnosis. GI will be used when we refer to those who were seeking help because of gender identity issues, but have not yet been diagnosed.

As a result of the debate on psychological health and GI, many studies have been conducted to assess the relationship between psychological functioning/psychiatric comorbidity and various forms of GI. Between studies, results vary widely. Some report a high prevalence of psychiatric comorbidity among transsexuals [8,19], whereas in other studies, psychological functioning of transsexuals was in the non-clinical range [16,17].

To assess the effectiveness of gender reassignment, a large number of follow-up studies have been conducted (see Pfäfflin & Junge [26], for studies until 1990, and Gijs & Brewaeys [14], for studies between 1990–2007) and showed that postsurgical outcome was relatively poor in some studies, and intermediate or satisfactory in other studies.

The Standards of Care of the World Professional Association for Transgender Health (WPATH) are, in most centres, used as guidelines for the clinical management of GID/transsexualism [18]. In these guidelines, the DSM and ICD are used to classify the diagnoses of GID (DSM-IV-TR) [1] and Transsexualism (ICD-10) [31]. However, there is still a lack of clarity with respect to the way clinicians weigh diagnostic indicators to come to a diagnosis of GID/transsexualism. The previously mentioned inconsistencies in findings regarding psychological functioning and treatment outcome may well result from differences in the way clinicians

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make their diagnoses or from differences between clinics in diagnostic procedures. Unfortunately, with regard to reliability, no research exists.

Besides differences in diagnostics, other factors, such as country/clinic differences in type of referrals (e.g., with respect to age of GI onset or sexual orientation), or in the attitude towards GI and concomitant differences in stigmatization may also play a role in the variability of study results. In single clinic studies, the influence of such factors on the study results cannot easily be determined.

In order to obtain more transparency in diagnostics and treatment of GI, four major West European gender identity clinics have initiated a collaboration in the "European network for the investigation of gender incongruence" (ENIGI). To facilitate cross-country and cross-clinic comparisons, the participating gender identity clinics (Amsterdam, Ghent, Hamburg, and Oslo) now have one diagnostic protocol and use the same assessment battery. The intention is to also develop a common hormone treatment protocol in the near future. By using similar instruments and procedures, the collaborating clinics aim to gain better insight in the phenomenon of GI and its treatment effectiveness, and to explain some of the contradicting findings in the literature. A further advantage of this collaboration is that data can be collected faster in this rare condition than when each centre would work separately.

The research topics that will be addressed in this collaborative project regard:

1. A description of applicants for treatment of GI in the four clinics.
2. The outcome of the diagnostic process in the four clinics.
3. Psychological functioning/psychiatric comorbidity of applicants for treatment of GI.
4. GI subtypes.
5. Factors predicting post-treatment outcome.

The aims of this first article are to present the procedures and instruments that will be used in this collaborative study, and to describe the first 271 applicants for treatment of GI in the four participating gender identity clinics.

2. Materials and methods

2.1. Subjects

In Ghent, Hamburg, and Oslo all applicants with GI of 16 years and older were asked to participate in this study. In the Netherlands, only GI applicants of 17 years and older were asked to participate, as 16-year-olds already participated in another study. Applicants with insufficient command of the respective languages, applicants who already had undergone some form of medical treatment (hormones or surgery), and applicants who were clearly psychotic when seen at first entrance were not invited.

2.2. Procedure

The principle researchers first agreed upon a diagnostic procedure that would be as similar as possible among the three institutions. Due to the specific clinical context at individual institutions, this was not possible in all respects. Subsequently, a number of instruments were selected that measured the main concepts for this study that were feasible for all centres to use in their respective clinical settings.

The ethics committees of all four collaborating clinics approved the study. Written informed consent was obtained from study participants according to institutional guidelines.

3. Instruments

Considering the main research questions, the following instruments have been chosen:

GID symptoms and background variables:

- A *background data interview* (MtF and FtM version). This is an adjusted version of the Dutch BVT (*Biografische Vragenlijst Transseksualiteit,* in English: Biographic Questionnaire on Transsexualism) [29] with questions about sociodemographic characteristics, social contacts, psychological and physical problems, family problems, gender development, cross-dressing, sexuality, and desired treatment. For many years, this instrument has been used as a part of the diagnostic procedure in the Amsterdam and Ghent clinics.
- The *Utrecht Gender Dysphoria Scale* (UGDS). This scale consists of 12 questions to measure the degree of experienced gender dysphoria [6].
- The *Body Image Scale* for evaluating transsexuals. This scale consists of 30 items to determine satisfaction with various body parts [24].
- The *Gender Identity Questionnaire*. This questionnaire has 22 items and four scales (male gender identity, female gender identity, 'certainty to belong to a gender,' and transgender identity) [27].
- The *Gender Identity/Gender Dysphoria Questionnaire for adolescents and adults*. This instrument consists of 27 questions regarding gender identification during the last 12 months [10].
- The *Hamburg Drawing Body Scale*. This scale measures the satisfaction with different body-parts with the help of a schematic drawing [3].

Psychological functioning/psychiatric comorbidity of applicants:

- The *SCL-90-R, Symptom Checklist*, assessing self-reported psychological burden on nine symptom scales: somatisation, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoneuroticism [11].
- The *MINI-PLUS* interview assessing DSM axis I disorders [28].
- The *SCID-II* interview assessing DSM axis II disorders [13]
- The Global Assessment of Functioning (*GAF*) assessing DSM axis V [12].

Measures also to be used for assessing postoperative outcome:

- The *SF-36*, measuring health-related quality of life on eight dimensions: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health [30].
- Two scales measuring aspects of general quality of life: "*Life as a whole,*" [4] measuring general satisfaction with one's life, and the *Social Readjustment Rating Scale* [20], a rating scale with 43 social and life events that may have happened in the last six months.
- The *physical appearance scale*. This is a rating scale for the subjective appraisal by an observer of a person's gender (in-)compatibility in physical appearance [29].

Use of symptoms to come to GID/GID related diagnoses:

- A self-constructed score-sheet with 23 items based on the DSM-IV-TR symptoms and diagnostic criteria to be filled out by the clinicians after they have made a diagnosis.

Potential predictors of outcome:

- A short self-developed list of potential risk factors, according to the clinicians, to be filled out at the moment of referral for hormone treatment.

4. Clinical procedures of the four clinics

4.1. VU University Medical Centre, Amsterdam, The Netherlands

The multidisciplinary Amsterdam team started to provide diagnosis and comprehensive treatment (psychological/psychiat-

ric, hormonal, and surgical) in 1975. On average, 140 adults apply for gender reassignment every year. Since 2002, an average of 35 children and 45 adolescents with gender dysphoria are referred yearly.

Diagnostic work is done by six psychologists with the possibility to consult a liaison psychiatrist. The mean duration for the diagnostic procedure is approximately 8 months with monthly visits during this period. After the diagnostic work is finished, the applicant is discussed by the multidisciplinary team and the team decides whether he/she is eligible for cross-sex hormone treatment. During hormone treatment, the applicant is seen every 3 months by an endocrinologist and a psychologist. After a minimum of 12 months of hormone treatment, plus "Real Life Experience," (a phase meant to give a person the possibility to experience functioning in the desired gender role on a daily basis) the team decides whether the person is eligible for mastectomy, ovariectomy and uterus extirpation (FtM's), or breast augmentation, as well as procedures like reduction of the Adam's apple (MtF's). Finally, after 18 months of "Real Life Experience", the team decides on external genital surgery.

Public funding is available for diagnostics, hormonal therapy, breast removal, and genital surgery. Breast augmentation is not covered. Facial hair removal is covered up to 10 treatments, and public funding is available for psychotherapy and speech therapy. Facial surgery is only covered in exceptional cases.

The Amsterdam clinic uses the DSM IV-TR [1] classification system.

4.2. University Hospital Ghent – Ghent, Belgium

The gender identity clinic of the Ghent University Hospital, Belgium, has evaluated and treated persons with GI since 1985. In the first years of the clinic, only a few people found their way to the clinic (about 10 applicants a year). Since 1999, the number of applicants seeking treatment for GI has increased to 35 per year. Eighty-five percent of the applicants come from Flanders, the Dutch speaking part of Belgium. The remaining 15% lives in the French-speaking part. During the diagnostic phase (a nine-month period), applicants are evaluated by one of two psychiatrists of the team in six to eight sessions. In case of doubt concerning the GID diagnosis, or in case of severe comorbidity, a second-opinion is asked from the other psychiatrist of the team. During the hormonal treatment psychotherapeutic support is given every two months. After 18 months of hormonal treatment, the applicant is referred to the surgeon. Postoperative psychological support is available on request.

Costs of psychiatric consultations, hormonal therapy, genital surgery, and breast-augmentation and removal are reimbursed. Costs of facial hair removal, female feminisation surgery, and speech therapy are not covered.

The Ghent clinic uses the DSM IV-TR [1] classification system.

4.3. University Medical Centre Hamburg-Eppendorf, Germany

The Hamburg clinic began seeing people with GI psychotherapeutically in 1972 (date of first application for gender reassignment). On average, 47 new applicants seek treatment per year. Some of them already had some form of medical treatment in other German centres. The Hamburg clinic focuses more on psychotherapy than the other three clinics in this study, which may imply that individuals do not primarily come to the clinic because they want hormones and/or surgery, but other types of treatment (e.g., psychotherapy). The diagnostic work is done by three specialised clinicians (two psychologists and one psychiatrist, all psychotherapists). After the first sessions, the collaborating endocrinologist screens the person for endocrine disorders and disorders of sex development. Appointments are made every three to four weeks. The diagnostic process includes making the diagnosis, psychotherapeutic support, and clarification of therapeutic goals. The clinician/team decides whether cross-sex hormone treatment is indicated. Psychotherapeutic support is continued during hormone treatment.

The costs for treatment are generally covered by health insurance, but applicants need two letters of recommendation from qualified clinicians. Germany's public health plan covers the costs for hormonal treatment and surgery of primary sex characteristics. However, breast augmentation for transsexual/transgender patients is usually not covered by German health insurance companies, except in exceptional cases. Further expenses such as the reduction of the Adam's apple or hair removal (MtF) have to be discussed with the health insurance company separately, and may be at the applicant's expense.

Diagnoses are classified according to the International Statistical Classification of Diseases and Health Related Problems (ICD-10) [31].

4.4. Rikshospitalet, Oslo, Norway

The gender identity clinic at the National Hospital in Oslo has been evaluating and treating adult individuals with GI since 1967. The gender clinic evaluates Norwegian gender reassignment applicants, regardless of age. Yearly 50–80 adult applicants are referred. During the diagnostic phase, all individuals are evaluated by two or more independent senior psychiatrists or psychologists. The mean duration for the diagnostic procedure is approximately 12 months, with monthly visits during this period. After the diagnostic work is finished, the applicant is discussed by a multidisciplinary team, and the team decides whether the applicant is eligible for treatment.

The "Real Life Experience" starts either during the diagnostic phase, or during the first year of the hormone treatment. During hormone treatment, the individual is seen every three months by an endocrinologist and by a mental health clinician (psychologist, psychiatrist, or psychiatric nurse). If there are no contraindications after one year of hormone treatment, the individual will be referred for surgery. Psychological follow-up evaluations are offered every sixth month until the last surgery, and three interview sessions are available up to five years after the last surgery.

Norway's public health care system covers all treatment steps, except for facial hair removal and facial surgery.

The Norwegian team uses the DSM-IV-TR system [1].

5. Data handling and statistical analyses

The data were scored locally for clinical purposes. Questionnaires from the participating centres were scanned at regular intervals using the Teleform format, and data were automatically transported into a SPSS database.

All analyses were done using SPSS 15.0 software. Between-group differences of variables measured on the nominal level were analyzed with chi-square tests. Analyses of variance were used for the analyses of between-group differences of ratio and interval data.

6. Results

In July 2009, sociodemographic data of 271 applicants (17 years and older) for treatment of GI were entered in our central database; 165 were males and 106 were females. There were 11 16-year old applicants in Oslo, one in Ghent, and one in Hamburg, but they were excluded in the current report in order to keep data comparable between clinics.

Table 1
Applicants for GI treatment at the four participating centres.

	Amsterdam		Ghent		Hamburg		Oslo	
	Males	Females	Males	Females	Males	Females	Males	Females
Number of applicants	89	38	30	12	21	28	25	28
Number of dropouts, *n* (%)	28 (31.5%)	7 (18.4%)	2 (6.7%)	1 (8.3%)	3 (14.3%)	1 (3.6%)	4 (16%)	2 (7.1%)
GID diagnosis, *n* (%)*	57 (64%)	29 (76.3%)	27 (90%)	11 (91.7%)	12 (57.1%)	22 (78.6%)	4 (16%)	12 (42.9%)

* Seven applicants in Hamburg (2 males, 5 females) and 9 applicants in Oslo (3 males, 6 females) are still in the diagnostic phase.

Table 1 shows that, of the 271 applicants, 48 individuals dropped out during the diagnostic phase (17.7%). In total, 174 applicants had a full GID diagnosis in adolescents/adults (64.2%): 67.7% in Amsterdam, 90.5% in Ghent, 69.4% in Hamburg, and 30.2% in Oslo. At the time of data analysis, the diagnostic procedure was not finished for seven applicants in Hamburg (2 males, 5 females) and nine applicants in Oslo (3 males, 6 females). Study participants' characteristics are listed in Table 2.

6.1. Sex ratio

There are noticeable differences in the applicants' sex ratios (males:females) between Amsterdam and Ghent on the one hand, and Hamburg and Oslo on the other hand. Amsterdam and Ghent registered a majority of natal males (respectively 2.34:1 and 2.5:1), whereas in Hamburg and Oslo the sex ratio was more balanced (respectively 1:1.33 and 1:1.12; Table 2).

6.2. Age

Both males and females in Amsterdam had the highest average ages, the youngest were the males and females from Oslo (Table 2). There was a significant difference in age for males ($F(3,161) = 2.78$, $p = .043$) as well as females ($F(3,102) = 4.08$, $p = .009$) between the four clinics.

6.3. Living situation

The highest percentage of males living on their own was in Oslo. In Ghent, only 8.3% percent of females were living on their own. We did not find significant differences between the four clinics in percentages of males or females living on their own.

6.4. Education

In all four countries, the majority of applicants had reached a medium educational level. However, there was a difference in educational level between the clinics ($\chi^2(6) = 22.29$. $p = .001$). The highest percentage of individuals with a low education level was found in Oslo (37.7%). The highest percentage of highly educated individuals was found under the Belgian applicants (33.3%), whereas Hamburg (8.2%) and Oslo (9.4%) saw relatively low percentages of highly educated applicants. In Amsterdam, 22.2% of the applicants were highly educated. For percentages of educational levels for males and females, see Table 2.

6.5. Employment status

All individuals who reported full/part-time employment or education where considered employed. Everyone reporting sick leave, early retirement, or unemployment was considered unemployed. We did not find differences in employment status for either males or females between the four clinics. On average, 66% of the applicants were employed.

6.6. Sexual orientation

Natal males, who reported to be solely or primarily attracted to males, and natal females who reported a sole or primary attraction to women were classified as androphilic/gynephilic respectively (Kinsey scales 1 and 2) [21]. All other males were classified as non-androphilic (natal males attracted to females, both sexes etc.) or non-gynephilic (natal females attracted to males, both sexes, etc.). The majority of male applicants reported a non-androphilic sexual orientation in all four countries, whereas the majority of female applicants reported a gynephilic sexual orientation. We did not find a significant difference in the percentages of natal males and females with same-(natal) sex attraction between the four countries.

6.7. Age of onset

We found no differences in the reported age of onset of feelings of GI between the four countries.

Table 2
Sociodemographic variables, sexual orientation, and onset age of GI treatment applicants at the four participating centres.

	Amsterdam		Ghent		Hamburg		Oslo	
	Males (*n* = 89)	Females (*n* = 38)	Males (*n* = 30)	Females (*n* = 12)	Males (*n* = 21)	Females (*n* = 28)	Males (*n* = 25)	Females (*n* = 28)
Mean age (sd)	36.36 (13.56)	31.34 (11.47)	35.53 (9.35)	28 (7.82)	31.71 (11.01)	28.57 (10.09)	28.92 (12.27)	23.11 (5.83)
Age range	17–75	17–54	19–48	18–40	18–49	17–60	17–56	17–41
Living on their own (%)	38.6	39.5	42.9	8.3	38.1	14.8	44	32
Education[a] (%)								
Low	29.5	21.1	3.3	16.7	28.6	17.9	32	42.9
Middle	45.5	63.2	60	58.3	57.1	78.6	56	50
High	25	15.8	36.7	25	14.3	3.6	12	7.1
Employed[b] (%)	65.9	72.2	78.6	72.7	61.9	61.5	66.7	48
Sexual orientation (% "homosexual")[c]	38.2	83.3	17.2	91.7	42.9	78.6	31.8	92.9
Mean onset age (sd)	10.48 (6.92)	9.97 (9.27)	11.12 (6.44)	8.10 (4.36)	9.38 (3.98)	9.16 (5.08)	11.36 (10.88)	8.50 (4.16)
Onset age range	1–37	3–48	4–28	3–15	3–16	3–24	3–56	3–16

[a] Low: lower education and lower vocational; middle: secondary education, secondary vocational and high school; high: higher vocational, bachelor, master & PhD.
[b] Full-time and part-time employment and education.
[c] Homosexual: androphilic in natal males and gynephilic in natal females.

7. Discussion

This is the first report on an ongoing collaborative study comparing individuals with GI in four European clinics. The treatment applicants in the four countries showed similarities, but also important differences.

First, there were differences in sex ratios. Amsterdam and Ghent were visited by a majority of natal males, and Hamburg and Oslo were visited more by natal females. Because we are reporting on the first 1 1/2 year of data collection, sex ratios may change as a result of yearly fluctuations. However, with the exception of Norway (because no prevalence data from Norway have been reported yet), our sex ratios are in line with those reported previously on individuals with diagnosed GID [9,15]. The gender composition of the population visiting the gender identity clinics in the Dutch-speaking regions thus clearly differs from that in the two other countries.

Second, individuals attending the Amsterdam clinic appeared to be significantly older as compared to those in Oslo. This age difference should be kept in mind in future treatment evaluation studies, as a higher age at application has been found to be associated with less favourable post-treatment functioning [14,26].

Third, male applicants were generally older than female applicants. This is in line with previous studies, which have also shown that males have a higher age at application than females [5,8,15,29]. We found this sex difference in age within each country, but this finding does not imply that the average age of female applicants at all four centres was lower than the average age of male applicants at all four centres. For example, females from Amsterdam were, on average, *older* than the males from Oslo.

Finally, educational levels differed between clinics, with relatively low percentages of highly educated applicants in Oslo and Hamburg, and high percentages of highly educated individuals in Ghent. The particularly low educational level of the Norwegian female applicants might be a result of their young age; they may still be in some form of training. However, the Norwegian males, and both the German males and females were much older than Norwegian females, but still not highly educated. Another explanation for the relatively low educational levels in Hamburg and Oslo, is that better educated (and therefore more affluent and perhaps older) people are more inclined to look for treatment options elsewhere (e.g., private practices inside or outside the country), especially when living far away from the treatment centres of Oslo or Hamburg. In smaller countries, such as the Netherlands and Belgium, there is less of a need to seek treatment elsewhere.

We did not find differences in living situation or employment status of applicants between the four clinics, nor were there differences in numbers of sexual orientation or age of onset subtypes [22]. As we report on applicants for treatment, it may be that subtype ratios will change when the more extremely gender dysphoric GID group is considered. Interestingly, Lawrence [23] reported on a positive relationship between a countries' Individualism Index (IDV) and the percentage of non-androphilic (individuals sexually not attracted to males) MtFs; the more individualistic a country, the higher the percentages of reported non-androphilic MtFs. Norway was not included in this report, but another Scandinavian country, Sweden, was. As the Netherlands and Belgium have higher IDV's than Sweden and Germany, one would expect higher percentages of non-androphilic natal males in the diagnosed groups in these countries than in Germany and Norway.

In consideration of the growing interest in and debate on the larger spectrum of gender incongruent conditions (see Cohen-Kettenis & Pfafflin [7] and http://www.dsm5.org [2]), we think it is important to report the sociodemographic characteristics of the entire group of applicants entering the gender identity clinic including those who did not get a GID diagnosis (either because they did not fulfil criteria for GID or dropped out during the diagnostic procedure). In the current study, 35,8% did not get a GID diagnosis. However, most studies have investigated diagnosed and treated individuals with GID and not the more heterogeneous group of gender incongruent individuals who seek help for their gender identity issues. For an overview of sociodemographic and clinical characteristics of diagnosed and treated individuals with GID in several countries we refer to Gómez-Gil et al. [15].

The observed differences between participants from the four countries may result from a number of factors. We already mentioned the possibility that more affluent individuals look for ways to avoid the thorough but time consuming procedures of national clinics, which may be situated far from an applicants place of residence. Potential differences in treatment outcome may well result from a selection bias that is related to this aspect. Another potential source for our observed differences is that the clinics may differ with regard to assumed or actual acceptance policy. For instance, clinics that accept or are assumed to accept the elderly for treatment may have older applicants than clinics which are more restrictive in this respect. It may thus be that, even within Northern-Europe, relatively small cultural or clinic policy differences influence the populations applying for treatment at gender identity clinics. Whether these factors indeed explain potential differences in diagnostic outcome, psychiatric comorbidity, GID subtypes, or long-term treatment outcome needs to be investigated in our future studies. Combining data from the four centres will provide better insight in the contribution of cultural factors to the results of such studies than has thus far been possible in single clinic studies.

Conflict of interest

None.

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